

# The Culture of Autism

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## 1. INTRODUCTION.

### THE CULTURE OF AUTISM: FROM THEORETICAL UNDERSTANDING TO EDUCATIONAL PRACTICE

Culture refers to shared patterns of human behavior. Cultural norms affect the ways people think, eat, dress, work, understand natural phenomena such as weather of the passage from day to night, spend leisure time, communicate, and other fundamental aspects of human interactions. Cultures vary widely in these respects, so that people in one group might at times find those from another culture to be incomprehensible or very unusual. Culture in the strict anthropological sense is passed on from one generation to the next; people think, feel, and behave in certain ways because of what others in their culture have taught them.

Autism is of course not truly a culture; it is a developmental disability caused by neurological dysfunction. Autism too, however, affects the ways that individuals eat, dress, work spend leisure time, understand their world, communicate, etc. Thus, in a sense, autism functions as a culture, in that it yields characteristic and predictable patterns of behavior in individuals with this condition. The role of the teacher of a student with autism is like that of a cross-cultural interpreter: someone who understands both cultures and is able to translate the expectations and procedures of the non-autistic environment to the student with autism. So to teach students with autism, we must understand their culture, and the strengths and deficits that are associated with it.

Autism is a developmental disability characterized by difficulties and abnormalities in several areas: communication skills, social relationships, cognitive functioning, sensory processing and behavior. Approximately 10-15% of individuals with autism have average or above average intelligence (including some whose IQs measure in the superior range); 25 - 35% function in the range of borderline to mild mental retardation, while the remain are moderately to profoundly mentally retarded.

The range of IQs reported in people with autism is one source of the tremendous variability in the population of persons who share this diagnosis; another source of variation is the scattering of skills within each individual. Most individuals with autism show a pattern of relative or even significant strength, usually in certain aspects of memory, visual perception, or unique talents (e.g. , drawing, perfect musical pitch.)

Because the organically-based problems that define autism are not reversible, we do not take "being normal" as the goal of our educational and therapeutic efforts. Rather, the long-term goal of the TEACCH program is for the student with autism to fit as well as possible into our society as an adult. We achieve this goal by respecting the differences that the autism creates within each student, and working within his or her culture to teach the skills needed to function within our society. We work to expand the skills and understanding of the students, while we also adapt environments to their special needs and limitations. In effect, what we attempt to do for them is what we ourselves might wish for when we travel in the foreign country: while we might try to learn some of the foreign language and gather information about the customs of the country, such as the monetary system or how to find a taxi, we would also be very glad to see signs in English, and have guides who could help us through the process of buying a train ticket or ordering a meal. In the same way, educational services for students with autism should have two goals: 1) increase their understanding; and 2) make the environment more comprehensible.

To achieve these goals of helping people with autism function more adaptively in our culture, it is necessary to design programs around the fundamental strengths and deficits of autism which affect daily learning and interactions. This approach to autism is related to, but different from, identifying deficits for diagnostic purposes. The diagnostic features of autism, such as social deficits and communication problems, are useful in distinguishing autism from other disabilities, but are relatively imprecise for the purpose of conceptualizing how an individual with autism understands the world, acts upon his understanding, and learns. Following are the

fundamental features of autism that interact to produce the behaviors which comprise the "culture" of this disorder.

The difficulties to be described below are not unique to autism. Many of the characteristics seen in autism are seen in other developmental disabilities, such as mental retardation, learning disabilities, and language disorders. Some are seen in certain psychiatric conditions, such as obsessive-compulsive disorder, schizoid personality, and anxiety disorders. Many are also seen in normally developing children, or even in ourselves. What distinguish autism are the number, severity, combination and interactions of problems, which result in significant functional impairments. Autism is the composite of the deficits, not any one characteristic.

## 2. THINKING.

**1. Lack of concept of meaning.** The primary problem that characterizes the thinking of individuals with autism is the inability to impose meaning on their experiences. They can act on their environment, they can learn skills, some can learn to use language, but they have no independent capacity to understand what many of their activities mean. They don't draw relationships between ideas or events. Their world consists of a series of unrelated experiences and demands, while the underlying themes, concepts, reasons, or principles are typically unclear to them. This severe impairment in generating meaning probably relates to several other cognitive difficulties.

**2. Excessive focus on details, with Limited Ability to Prioritize the Relevance of Details.** Students with autism are often very good at observing minute details, particularly visual details. They frequently notice when objects in their environment have been moved, they may see tiny scraps of trash to be picked up, threads to be pulled, flaking paint to be picked, ceiling tiles to be counted, etc. Some also notice other sensory details, such as the sounds of fans or machinery. Individuals who function at a higher level of intelligence usually focus on more cognitive details, such as call letters of radio stations, area codes of telephone numbers, or capitals of counties. What students with autism are less capable of is assessing the relative importance of all the details they have noted. They might focus on the sight of the string they are dangling while crossing the street, and miss the approach of an oncoming bus, or they might enter a room and comment on the sounds of the fans, which ignoring the fact that lunch is on the table.

**3. Distractibility.** It is frequently difficult for students with autism to pay attention to what their teachers want because they are focusing on sensations which to them are more interesting or important. In addition, their focus often switches rapidly from one of these sensations to another. Often the sources of the distraction for lower-functioning children are visual: A teacher might put a pencil on the desk, and the child is so distracted by the pencil that he does not attend to his work. Or the student sees something out the door and is so distracted that he stops working in order to watch more closely. Auditory stimuli can also be very distracting. A student may hear a noise that the teacher doesn't even hear, from five rooms away, and become unable to concentrate. Some students with autism are also apparently distracted by internal stimulation, such as a desire for the stick, string, cup, or other object that they remember from past experiences. Or they might be distracted by internal cognitive processes such as rhyming, counting, computing, or reciting facts they have memorized. Whatever the source of the distraction, people with autism have great difficulty interpreting and putting in priority the importance of external stimulation or thoughts that bombard them. Some look, move, and explore constantly, as if all sensations are equally new and exciting, which for them they are. Others deal with this bombardment by appearing to shut out much of the stimulation around them, becoming preoccupied with a very limited array of objects.

**4. Concrete Thinking.** Individuals with Autism, Regardless of their cognitive level, have relatively greater difficulty with symbolic or abstract language concepts than with straightforward facts and descriptions. In the culture of autism, words mean one thing; they do not have additional connotations or subtle associations. An example of this was is a 15 year-old man with an average IQ, who was asked the meaning of "the early bird catches the worm." He replied, "if a bird wakes up early in the morning, he can catch a worm if he sees it and if he catches it, he eats it right up, and then he goes on and he looks for another worm." Similarly, when asked the meaning of "don't cry over spilled milk," he answered, "if you spill milk you shouldn't cry over it but you should pick up a rag, you should mop it up and then clean the rag and then go have some more milk."

**5. Difficulty With Combining or Integrating Ideas.** It is easier for people with autism to understand individual facts or concepts than to put concepts together, or to integrate them with related information, particularly when the concepts appear to be somewhat contradictory. For example, a young man went on regular camping trips to a place called Camp Dogwood. Most of the camping trips were in the fall and early spring, never when the dogwoods were flowering. Each time this young man came to Camp Dogwood he expressed his wish to see them flowering. Finally he got his wish when his group went to Camp Dogwood in April. Knowing how long he had waited, the woman who managed the camp placed a dogwood blossom on his plate, so he could find it when he came down for breakfast on his first morning. The young man picked up the dogwood flower and marched straight to the kitchen looking for the manager, apparently to thank her. Instead, he gave her a long lecture about the importance of protecting nature (he was a member of an environmental club) and the inappropriateness of Picking flowers. When it was explained to him that she was a nice woman who had picked the flower as a gesture of affection, he insisted that if she were nice she would want to know that hurting the environment is wrong, so scolding her was doing her a favor. He could not understand how two inconsistent concepts (nice people save the environment and a nice person picked flowers) could both be accurate.

**6. Difficulty With Organization and Sequencing.** Related to the general difficulty integrating multiple information are the problems with organization and sequencing. Organization requires the integration of several elements to achieve a predetermined end. For example, if one is planning a trip one needs to anticipate what will be needed in order to pack all of these items in a suitcase before leaving. Another example would be the need to collect all of the necessary materials before successfully completing a task. Organizational skills are difficult for people with autism because they require the ability to focus on both the immediate task and the desired outcome at the same time. This kind of dual focus is what people attending concretely to specific, individual details don't do very well.

Sequencing also is difficult for people with autism because it requires similar skills. It is not unusual for people with autism to perform a series of acts in illogical, counter-productive order, and seem not to notice. For example, a person might get up in the morning, comb his hair, then take a shower and wash his hair. A person making lunch might take two slices of bread and then put meat on top, instead of bread and meat then bread as we typically do in our culture. Sometimes they put their shoes on before their socks. In these ways they show us that while they have mastered the individual steps in a complex process, they do not understand the relationships among the steps, or the meaning of the steps with regard to the final outcome.

**7. Difficulty With Generalizing.** People with autism often learn skills or behaviors in one situation but have great difficulty generalizing these to a different situation. For example, they might learn to brush their teeth with a green toothbrush, and then balk at brushing their teeth with a blue toothbrush. They might learn to wash plates but not realize that the same basic procedure is used to wash glasses. They might learn the literal wording of a rule but not understand its underlying purpose, and so have trouble applying it in different situations. For example, a high-functioning young man used to go into the building where he works, very early in the morning, to change his clothes. He was told that even though the building had not officially opened there were still people there busily getting ready for the workday. These people did not want him changing his clothes in full view of them. He apparently understood this, but what he began to do was change his clothes out in the parking lot, in full view of everybody passing by. He honestly did not understand the concept behind the request, because he had difficulty knowing from other perspectives when he could be seen changing his clothes and when he could not.

In addition to multiple cognitive deficits, autism has certain characteristic bio-behavioral patterns:

1. Strong impulses. Persons with autism are often extraordinarily persistent in seeking out the things they desire, whether these are favorite objects, experiences, or sensations such as touching something, performing a complex ritual, or repeating an established behavioral pattern. These behaviors, which resemble the symptoms of obsessive-compulsive disorder, can be very difficult for teachers and parents to divert or control. In fact, there is such a driven quality to them that they appear not to be under the conscious control of the autistic individual. Directing, controlling and channeling these behaviors is a major challenge.

2. Excessive anxiety. Many people with autism are prone to high levels of anxiety; they are frequently upset or on the verge of becoming upset. Some of this anxiety is probably attributable to biological factors. In addition, anxiety can result from frequent confrontations with an environment that is unpredictable and overwhelming.

Because of their cognitive deficits, people with autism often have difficulty understanding what is expected of them and what is happening around them; anxiety and agitation are understandable reactions to this constant uncertainty.

3. **Sensory/perceptual abnormalities.** The field of autism has known for many years that the sensory processing systems of people with autism are unusual. We see people with very unusual food preferences, people who spend their time watching their fingers flick, or rubbing textures against their cheeks, or listening to unusual sounds very close to their ears so that they can also feel the vibrations. We know people with autism who don't respond to sounds the ways others do, causing others to think they are deaf when they have perfect hearing acuity. Some people with autism seem to confuse the feelings of being pinched with being tickled, or appear not to feel pain at all. Others choose to rock back and forth for hours in repetitive patterns. In many different ways, people with autism show us that their differences begin at the level of processing some or all the sensations that impinge on their body every waking minute.

#### TEACCH Educational Principles.

Given the characteristic cognitive and behavioral patterns of autism, the TEACCH Program has developed ways to help individuals with autism function in the culture that surrounds them. With more than twenty years of working with these issues, Division TEACCH has created educational programs that have been extremely successful in meeting this goal. The TEACCH educational program is based on several principles:

**1. Strengths and interests.** All students have strengths and interests that can be made more functional for them. For example, if a student is strongly attached to the color red, the most important parts of his work can be marked in red. For students who are very attentive to visual details, we teach matching, sorting, and collating skills that can be used in real-life employment situations. We can rely on a student's compulsion to complete tasks in a set sequence to teach the use of checklists for a variety of jobs, such as personal care, household chores, vocational skills, and even leisure skills. While we cannot change the autism, we can use it as a context to help the student acquire the skills required by our culture.

**2. Careful, On going Assessment.** All students have the potential to develop better skills. From the severely retarded, nonverbal child with problems of hygiene and aggression, to the high-functioning individual who can read, write, and spend time alone in the community, all students with autism have gaps in skills, and all have potential for progress. In the TEACCH program, we begin the process of designing an educational program by observing the student's approach to a variety of materials, directions, and activities, presented in different modalities with different amounts of structure. We pay particular attention to the areas of communication, self-care, vocational skills, and recreation/leisure skills. Needs are prioritized, and then goals are set in each area.

**3. Assistance Understanding Meaning.** All students with autism have limitations in their ability to understand the meaning of their experiences. As previously stated, difficulty with understanding meaning is central in autism. We cannot ever assume that our students understand why we ask them to do certain things, how the skills and behaviors we teach them are related, or even what, specifically, we are requesting. Even the most intelligent students with autism are frequently confused or uncertain about expectations and customs in our culture. Teachers must not lose sight of the student's constant need for an empathic, helpful guide to our confusing and difficult to interpret environment.

**4. Non-compliance resulting from Lack of Understanding.** Most of the behavior that students display is due to their cognitive difficulty in understanding what is expected of them. It is extremely rare, in our experience, for a student with autism to be deliberately defiant or provocative. Unfortunately, some observers interpret their behavior in this way, particularly when the student with autism looks right at them and then does the opposite of what was asked, or does what was just forbidden. In other students, we might rightly suppose that such behavior is performed to express anger, or to assert the independence of the student. These are rarely the appropriate explanations for such behaviors in students with autism; however, it is much more likely that the student does not understand the words used, the facial expression and body language of the speaker, or the social expectations of the situation. The student might be driven by strong impulses to act regardless of rules or consequences, or might be agitated and overwhelmed by sensory stimulation in the room. The rules might be too abstract or too vague. Non-compliance is rarely a useful concept in autism.

5. **Parent Collaboration.** Educational planning should be sensitive to the environment where the student goes home at night, and will live as an adult. It is important to incorporate the wishes and lifestyles of the student's family into the educational program. If the parents want or need the student to eat dinner with the family or productively occupy his leisure time, we try hard to attempt to teach these skills.

### TEACCH Educational Goals

If we are correct in conceptualizing the primary cognitive deficit of autism as a problem of understanding meaning, then it follows that a primary educational goal is to teach the student that his environment does have meaning. It is not sufficient to teach compliance with a teacher's requests, compliance with rules, or skills with materials or language, because teaching a variety of behaviors and skills that are unrelated, in the student's view, does not address the basic problems of failure to understand, make connections, and generalize. Our most important goal is for our students to find that there are patterns in the universe, and that they can identify and follow these patterns regardless of the presence of a teacher or familiar adult. Although teachers are the ones who enable their students to achieve this goal, ultimately we want students with autism to be able to function without intensive supervision from a teacher, for the simple reason that our culture does not provide resources for life-long teachers. Thus, the educational goal of teaching the student to find meaning and order in his world is a practical reflection of the general goal of helping the student fit into our culture as an adult.

Another educational goal is teaching the student the concept of cause and effect. While all normally developing children and many persons with autism learn this at a young age, some students with autism, particularly those who have significant mental retardation, do not understand that they can cause events to happen in reliable and predictable ways. This is a key concept in our culture's understanding of the universe that is lacking among some people with autism. It is a prerequisite for communication, and it is important in other skills, for example for understanding how to dress (when I pull, the shirt comes over my head), or how to use materials (when I move the rag, the dirt disappears). Mastering cause and effect results in a tremendous advance in the ability of the person to care for himself, do productive work, and live in a community.

Communication is an extremely important educational goal for all students. Some students with autism must first be taught that communication exists, that it is possible for one person to influence the behavior of another by some expressive act. The nature of this act can be individualized to the level of the student, with a range of options that include making a sound, ringing a bell, exchanging an object, exchanging a picture, saying words, typing words, or using gestures or symbolic signs. Students who have some skills in communication can and should be taught refinements, such as additional vocabulary, more complex sentence structures, or expanded language systems (e.g., written as well as spoken language).

TEACCH educational goals are also planned to develop meaningful skills for adult life. Skills and behaviors are not targeted for their own sakes, but for their functional utility for the future of the individual. Even with very young children, we attempt to teach the foundation skills for as much independence as possible in the areas of self-care, communication, vocational skills, leisure and recreational interests, and community living. So we focus our educational day on very concrete events: using the bathroom, putting on shoes, asking for help or something to drink, sorting, matching, and collating materials, wiping tables, turning on music, working a puzzle, walking to a restaurant, riding the bus to a swimming pool.

### LIMITATIONS OF TRADITIONAL EDUCATIONAL TECHNIQUES

The simplest and most effective way to teach students without autism is through the use of language. Teachers in regular classrooms talk all day long, explaining every facet of the skills to be mastered: how to use scissors, how to ask for help, how to write a sentence, how to solve an equation. While verbal explanations work well for most students, for students with autism they are often ineffective, and occasionally counter-productive. This is true irrespective of the cognitive level of the student. Even students with extensive expressive vocabularies might have very limited ability to attend to or process the teacher's verbal explanation. They might not know they are being spoken to, they might be watching the pattern of the teacher's lips moving, they might be thinking about the sound of the fan in the room, etc. Even if they are paying attention, they are likely not to understand language containing idioms, subtle connotations, logical inferences, or complex vocabulary. Students who have mental retardation in addition to autism are even less likely to learn effectively through

verbal means. This is not to say that teachers should not use language as one educational modality, but reliance on this modality alone will likely be unproductive and frustrating for both teacher and student.

In conjunction with or instead of verbal instructions in our culture, we often show students what we want them to do. Unfortunately, this technique is typically ineffective for students with autism, because it depends on the student's ability to attend to the demonstration and identify the relevant aspects of it. For example, the teacher might want Billy to copy the way another student hops on one foot. But Billy might think that the concept being taught is to have orange shoe laces like the other student, or to make the same noise as he did, or to have bumpy knees like the other student. Or he might see the other student's behavior, but have no idea how to organize his own behavior to look the same way. And of course he may have no idea what the teacher has said, or whom he is supposed to be watching.

In our culture, we generally reward students' achievements with social responses, such as praise, smiles, pats on the back, and other acts that communicate "I am proud of you." These acts depend on the ability of the student to decode the symbols of the teacher's pleasure, and on the meaningfulness to the student of the teacher's pride. But a student with autism may not understand the communicative intent of a smile, a sticker, a hug, etc. Or he may not find a teacher's expressions of satisfaction to be relevant or meaningful. So social reinforcement often has limited effectiveness with our students. While we usually provide it, we must in addition use other methods that are more meaningful to students with autism.

The difficulties that students with autism have in learning from traditional educational techniques most certainly do not mean that they are incapable of learning, or that no effective educational techniques exist. The limitations of traditional techniques simply mean that different techniques and strategies must be used with these students.

#### TEACCH Educational Techniques.

Of all the educational techniques we use, reliance on visual presentation of information is the most important. As described above, verbal explanations alone are rarely effective for students with autism. Words can be used, physical prompts may be helpful, but materials and physical structure that visually lead the student toward understanding and success are by far the most effective. In any modality complex presentations of large amounts of materials are likely to be confusing, overwhelming, or incomprehensible to the student. Therefore, we also teach the student the strategies of working from top to bottom and left to right. This spatial organization is culturally normal for us, and so we organize as much of our students' classroom experience as possible in this fashion. For example, they find the component parts of their work at the left, and put finished products to the right.

We also rely on visual information, whenever possible, to teach students with autism the concept of finished. This is an important concept to incorporate in all activities because many students with autism, as part of their difficulty inferring the meaning of events, are unable to figure out how long an activity will last. This can be distressing to them, so they often impose their own view of how long or how little they will work. We attempt to show them, through visual means, how many repetitions of the activity they are expected to perform before the activity ends. Sometimes the materials themselves make this clear: when the box of component parts is empty, the work is finished; when you reach the bottom of the page, the work session is at an end. At other times, more creativity must be used to make the passage of time visible: for example, when a certain amount of time has elapsed, the teacher removes a clothespin from the student's sleeve or belt; when the clothespins are gone, the activity is over. Finishing an activity in a clear, definitive way is usually more satisfying to our students than receiving praise, stickers, candy, etc. In fact, it appears to us that when these rewards are used, they are more likely to serve the function of conveying "finished" than they are to be reinforcers that the student will strive for the next time.

Another educational technique used throughout the day is to teach routines with flexibility incorporated. There are three primary reasons for this. First, routines give the student a strategy for understanding and predicting the order of events around him, which generally decreases agitation and assists in skill development. Second, if the teacher does not provide routines, very often the student will develop his own, which might be less adaptive or acceptable. For example, the student might develop a routine of entering the classroom every morning and pulling all the coats off the coat rack, or might insist on licking all the spoons he sets out on the

lunch table, because this is what he did the first time. Routines such as "hang up coat, turn on music" or "put spoons down (with supervision) then go to the play area" can help to reduce undesired alternative routines. Third, the routines taught should be flexible because this reflects the reality of our culture. Our world is not invariable, which is what makes it so confusing to the person with autism. His attempts to make it so should be respected but gently challenged by the teacher, through the use of slightly different materials for work, paths taken for walks, games played, food presented, etc. The essential structure should remain predictable, but details should vary, so that the student is led to focus on the structure rather than on the details.

Individualization is a key concept in TEACCH educational programs. In spite of the features of autism that they have in common, our students are extremely different from one another, in terms of strengths, areas of difficulty, and idiosyncrasies. We find that our students do not learn well in a group, because of their varied skills and their difficulties with learning through observation of others. We must also remember that within our students, skill levels are generally not correlated to the extent they are in other students. For example, excellent skills in visual perception do not tell us anything about the student's language skills. Expressive fluency can mask significant receptive language gaps. Students who are capable of reading, cooking, and data processing might be unable to ask for a drink of water in public. Conversely, students with significant mental retardation and autism might be talented artists or musicians. Therefore, teachers must know their students extremely well, and be prepared to teach the same student at very different levels in different skill areas.

Our students' tendencies to over-focus on details and to resist change mean that we must do our teaching in varied settings, with varied materials, so that we can help them be as flexible as possible. Related to this, it is also important to teach skills in their natural settings, since the ability of our students to generalize is limited. Thus, we hope to teach work in the work-site, community skills in the community, food preparation skills in the kitchen, etc.

## CONCLUSION

Our job as educators of persons with autism is fundamentally to see the world through their eyes, and to use this perspective to teach them to function in our culture as independently as possible. While we cannot cure the underlying cognitive deficits of autism, by understanding them we can design educational programs that are effective in meeting the challenge of this unique developmental disability.